Special Issue on The Deepening of Disciplinary Content: Public Health in Post-COVID

India

RESEARCH

Making HIS More Agile, Relevant and Public Health Friendly: Lessons from COVID-19 in India

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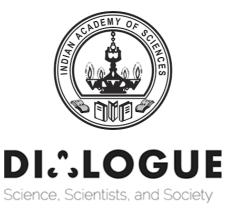


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Abstract. Anthony Giddens, the noted sociologist, describes the COVID-19 pandemic as a 'digidemic,' emphasizing the inextricable linkages between the pandemic and the digital (<u>Giddens 2020</u>). As the pandemic has spread globally, countries have adopted different strategies to leverage digital technologies, in their design, development, implementation, and governance to address the pandemic. Some of these strategies have worked well and others have not so. We submitted this paper at the time when India was fighting the first COVID-19 wave and are submitting this revised version as India fights a much tougher second wave. And between these two waves, we have witnessed some flattening of the COVID-19 curve and the onset of a rigorous vaccination drive. This paper aims to try to analyse some experiences of how countries leveraged digital technologies in their information systems response, such as from Sri Lanka, South Korea and anchored in a historical understanding of public Health Information Systems (HIS) in India, build key learnings for strengthening HIS in India, both for pandemic situations and also routine health management. These include i) improving

agility, reflecting the ability of the HIS to provide timely information for supporting local action; ii) improving relevance, implying providing required information for supporting the desired action for different stakeholders; and, iii) public friendliness, implying the HIS should help support population health at large in an equitable manner. We argue that these learnings are not only relevant for strengthening the HIS response to pandemic management but also more broadly for strengthening Indian public HIS covering routine systems. These learnings are particularly pertinent in the current 'digital' context in India, where large-scale interventions related to the National Digital Health Mission are currently being planned and implemented. For good or bad, the 'digital' is inevitable in public health systems globally, and it becomes important for researchers and practitioners to engage with this process of understanding the digital interventions and contribute to strengthening the health systems.

INTRODUCTION

Globally and in India too, the COVID-19 pandemic is still upon us, maybe making it a little premature to discuss learnings for the post-COVID-19 era. However, given the scope, scale and implications of the pandemic in India, and the many different and rapid digital interventions that have taken place to curb the spread, including the roll-out of the COVID-19 contact tracing and vaccination management related interventions, there are some clearly evident learnings. We focus on lessons around the 'digital,' which have been deeply implicated in these response efforts, particularly on how they can be effectively designed, innovated, implemented and governed. Arguably, these lessons, are not just limited to managing pandemics but can be made more broadly relevant towards making Indian public HIS more relevant and public health-friendly, particularly in the current context of the National Digital Health Mission (NDHM), which promises – for the good or bad – a future of 'digital health.' Our paper focuses on two flagship digital interventions – Aarogya Setu for contact tracing and CoWIN for vaccination – as a basis to discern learnings.

The COVID-19 pandemic is significantly different from earlier large-scale pandemics like the Bubonic plague (prominent outbreak in the 14th century) (<u>WHO 2000a</u>), the Smallpox (historically since 3rd century BCE, eradicated only in 1979) (<u>CDC n.d.</u>), flu (1918) (<u>CDC n.d.</u>) and the more recent SARS (in 2003) (<u>WHO n.d.</u>). Particularly unique, is the scale of the pandemic, with use, nature and scale of digital interventions, including related to: i) organising systematic and integrated information at country scale spanning levels from the national to the community; ii) its use in some unique ways, such as large-scale contact tracing with direct implications on citizen privacy and more recently the ongoing mass vaccine roll out; iii) unlike traditional HIS which were primarily for use by the state, the current efforts have been visible to all, in shaping decisions on lockdowns and distancing with direct socio-economic implications; and, iv) speed of digital response in design, development and implementation has been rapid, especially given the conditions of relative uncertainty given the unknown nature and implications of the disease.

These characteristics of the digital efforts have primarily involved a form of 'trial and error' approach globally, shaped by local contextual conditions, with some efforts achieving some success while others not so. It, thus, becomes important to understand some of the learnings from these efforts globally and draw key lessons to make HIS, in India more agile, relevant and public health-friendly. While agility implies the capability of the HIS to support timely action when and where it is most needed, relevance concerns the ability to provide the right information support for the problem on hand, and public health-friendly concerns the ability of the HIS to support the population at large in an equitable manner.

By drawing upon these key lessons, arguably the HIS could be strengthened not only for pandemic management but also for the national public HIS more broadly. In general, the attributes of agility, relevance and public health friendliness are generic and should be applied to all HIS. While the conditions of the pandemic provided particular contextual conditions within which the HIS have been designed and implemented, non-pandemic specific systems would need to be built taking into consideration the particular situation and learnings appropriately adapted.

In this paper, we discuss learnings under three main criteria of agility, relevance and public health friendliness. These are summarized in Table 1 below and then discussed:

1. Building agility	2. Building relevance and trust	3. Building public health and friendliness
Decentralized information for enabling local action	Sharing data in the public domain	Strengthening public health content in information for the public
Less data collection - doing more with less	Collecting relevant data to support action	Designing systems based on public health expertise
Enabling integration and data sharing across systems	Trusting the openness	Bringing public health into public discourse
		Demand-driven vs. supply-driven

Table 1 Key learnings for strengthening health information systems (HIS) response to pandemics

These lessons are now discussed.

LESSON 1: BUILDING AGILITY

Agility broadly concerns the speed by which decisions around the building and use of the HIS response are taken and implemented. We take agility to be shaped by the ability to provide decentralized information to support action.

Decentralized information for enabling rapid local action

In the Indian context, typically data collected at the community level flows to the national level and then reverts to the source of the data in the forms of reports to guide action. This dynamic is described by Mukherjee (<u>Mukherjee 2017</u>) in her study of the Mother Child Tracking System (MCTS) which captured data on pregnant women and children for immunization. The field-level health workers, called Auxiliary Nurse Midwife (ANM), enter by names details of pregnant women and children into the MCTS which was hosted in a national server. The data was then converted at the national level into relevant reports (such as the generation of ANM activity reports) and relayed back to the ANMs to help plan their work. Typically, this cycle of data flow would take a month or more, a very non-agile response, for the ANM who would need to take immediate action, particularly for certain cases, such as for ensuring the care of a high-risk pregnancy. However, for most of the routine reports such as giving details of pregnant women care or a child an immunization shot, the one-month delay may be relatively less crucial. In a pandemic, the need for agility and to support local care processes at all times is fundamental.

The context of the pandemic is very different from that of routine reporting, for example as implied in the MCTS. As Amartya Sen (2020) writes, "Overcoming a pandemic may look like fighting a war, but the real need is far from that." He adds, "What is needed for dealing with a social calamity is participatory governance and alert public discussion." Pointing out how every section of society deals with a pandemic differently and their worries vary, he says problems arise when "A single-minded pursuit of slowing the spread of the disease does not discriminate between different paths that can be taken in that pursuit." He ends by underscoring the emphasis on the act of listening and participatory governance. He adds, "Governance can be greatly helped by informed public discussion." (Sen 2020). Also, this has been emphasised by Gilson et al. (Gilson et al. 2017), who find benefit in participation for all, respectful communication, information sharing, collaboration, problem-solving in strengthening routine as well as emergency health systems.

The failure of centralized models is exemplified by the UK's contact tracing application. Booth (<u>The Guardian 2020</u>) describes how the UK 12 Billion Pound supposedly 'world-beating app' has ended up as a fiasco. The system was centralized by design, built by the consulting firm Deloitte, with very few public health inputs. Booth quotes a city Mayor:

"We've always known that there was a need for a local element of test and trace, as a centralised system does not have local expertise and is not able to cut through the harder-to-reach communities."

As a result of extreme centralization, the system was not able to contact more than 60% of the people identified to be contacted, potentially putting to danger, lives of thousands of citizens.

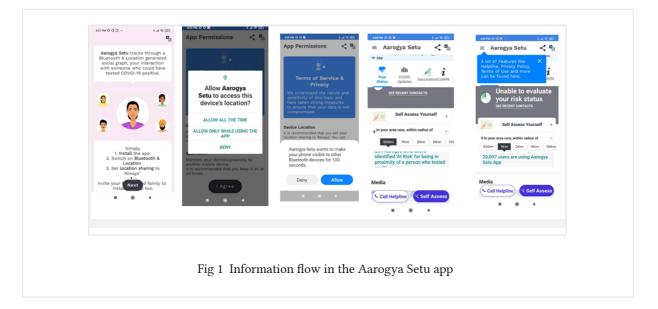
Though the Indian Constitution makes health a state subject, however, by expansively invoking the Disaster Management Act, the Centre gave itself vast powers in handling the first wave of coronavirus pandemic in 2020. Arguably, some degree of this centralization was required as the harsh national lockdown needed some measure of uniformity in what states were doing. However, soon states started to diverge in their local policies, such as Delhi announcing that majority of hospital beds in the state would be reserved for local residents. In the second wave, states took individual decisions on issues of lockdowns, curfews, and utilization of hospitals, taking more responsibility to deal with the pandemic and not relying on the Centre's support. This also reflects lessons learnt from last year's largely centralization policy which had millions of working-class migrants stranded in cities hundreds of kilometres away from their homes. Management of the second wave is witnessing more and more interstate cooperation/collaboration by sharing resources, knowledge and managing the homeless migrant population.

With respect to technology, a flagship e-governance initiative in India was the rollout of the COVID-19 contact tracing app, Aarogya Setu, in April 2020. Like the case in most countries, both developed and developing, the contact tracing app did not work effectively in India too. A key barrier to its success was related to citizen trust in the safety of their personal data and uncertainty of how their personal data was going to be used. This highlights the significance of citizens' confidence and trust in authorities and their perceived incentives from sharing their data. For citizens, awareness of risk, trust in data security, responsible data governance and perceived incentives, are key factors shaping their participation and consent to participate in surveillance efforts. For the state, tactics of coercion were used to enhance citizen participation by making the app 'mandatory' to access various services, including air travel and commuting on public transport within and between cities.

In December 2020, India launched the COVID-19 Vaccine Intelligence Network (CoWIN), a digital platform for 'supervising and managing' COVID-19 vaccination (<u>MeitY MoHFW Press</u> <u>Release 2020a</u>). Given that the purpose of the two platforms, CoWIN and Aarogya Setu, is completely different, so has been the citizen uptake of these two platforms. CoWIN platform is used to register for COVID-19 vaccination by sharing a phone number and a photo ID. While Aarogya Setu prompts you to keep safe by alerting if you are in the vicinity of a COVID-19 positive person, by sharing the phone number, updating your COVID status and allowing the app to track phones through the GPS location/movement. Interestingly, while personal details required for the Aarogya Setu app and CoWIN registration are similar, arguably the uptake of the two have been very different, with CoWIN being more accepted and by April 2021, 76 million total doses given to people, 10.2 million are fully vaccinated, and millions of Indian

citizens have registered in CoWIN for vaccination (CoWIN dashboard <u>https://</u><u>dashboard.cowin.gov.in/</u>). This raises the interesting question of why there are relatively different outcomes of these two apps, and what lessons can be discerned for strengthening of national HIS.

At the outset, there were some controversies around the Aarogya Setu app (see information flow of the app in Fig 1). After its release, there were sharp criticisms from activists and researchers who labelled the App as being non-transparent, invading users' privacy, risking the personal data of users, enabling undue surveillance of citizens, and even providing inaccurate data (The Hindu 2020). In response, on May 26, 2020, the government took the important step to declare the App as open-source, thus opening it up to public scrutiny and alterations could be proposed by the community. This move was expected to bolster the robustness of the App and 'privacy by design' (MeitY 2020b). However, as claimed by Internet Freedom Foundation (IFF) (Internet Freedom Foundation 2020), the App was not fully open source. While there may be technical disagreements around the nature of the App and whether its use was mandatory or not, a key positive learning is that the government, based on internal resources and capacities, designed, built and implemented an App at a huge scale in India in a relatively short duration from the onset of the pandemic. While these debates were ongoing, the fact is that contract-tracing apps did not work anywhere, including the Scandinavian countries where trust in governments is very high, primarily reason being that people considered being followed with their GPS locations as an invasion of their privacy (Sandvik 2020).



The COVID-19 has tested many a model and has given rise to debates on merits or not of centralized approaches like in the UK and US or relatively decentralised ones as adopted by Germany and Japan. Centralisation tends to limit the flexibility and efficiency of the information systems response while supporting the use of available infrastructure and resources. Decentralisation relies on the use of existing resources closest to the ground whilst enhancing the need for coordination and building consistency (Heitmueller and Roemheld 2020;

<u>OECD 2020</u>; <u>Sanchez 2020</u>; <u>WHO 2020b</u>). While centralization potentially can enable standardization, it will probably be less agile given the chain of bureaucracy involved. A decentralised approach leaves more flexibility in the space for a more aligned public-private partnership through the mapping of available skills and contributions with possibilities of ensuring the use of best practices. However, it does raise challenges of standardization and consolidation, while also being more resource-intensive than a centralized deployment.

Sri Lanka provides a best practice example of how they combined the positive features of centralization and decentralization to create great agility in their information systems response, described as a form of socio-technical agility (Amarakoon et al. 2020). They identified three key determinants for building this agility. The first concerned governance, where the government set up a high-level and inter-sectorial task force under the office of the President and consisting of the Director-General of Health Services, Defence Minister and similar senior officials from police and immigration. Such a high-level structure drew upon the power of the central to ensure important decisions, which normally would be tied down by bureaucratic hurdles, to be quickly taken. Furthermore, specialist task forces were created for implementing specific tasks, such as relating to building the HIS response. This helped to combine the central authority with decentralized capabilities for enabling effective implementation. The second concerned the historically existing *health informatics capacity*, which the ministry had invested in for over a decade by supporting their medical doctors to access free postgraduate health informatics education. These doctors after their study programme re-joined the ministry as 'health information officers' thus contributing to overall health systems strengthening and were key in building the current HIS response. This long-term capacity strengthening programme, was a centrally driven effort, which then contributed to strengthening decentralized informatics structures across the country. This effort of the government was a continuing strategy to invest in strengthening public systems, for example, their policies of providing its citizens free health and education (Sribaddana et al. 2019). The third concerned the use of the *free and open-source digital platform* (DHIS2 – see <u>dhis2,org</u>) which was already well-institutionalized in the country and the health information officers were well trained in the DHIS2 as a part of their educational programme. Given the opensource nature of the platform, the DHIS2 could rapidly be customized to the evolving needs of the pandemic, and the centralized decentralized hybrid structure facilitated its rapid implementation using the existing health systems and health informatics capacities.

Enabling integration and data sharing across systems

An important condition shaping agility is the capability of systems to share data with each other. Firstly, it saves time on re-entering data that may have already been collected elsewhere thus mitigating redundancies and duplications of work effort. Secondly, it allows for the generation of cross-cutting reports and indicators where data has to be collected and integrated across multiple systems. HISs in India has been historically limited in being interoperable with other systems, for both technical and institutional reasons. Despite the Government having a clear policy that all public systems should use open source platforms

and publicly release their APIs (Application Programming Interface) to enable data sharing, these policies have not been effectively implemented. For example, challenges have been experienced while working with various states in strengthening their routine Health Management Systems (HMIS) who are using a third system as their local data warehouse and would like to transfer at the end of the month the data required to the national portal. This API access has not been forthcoming, implying states have to generate spreadsheets of the monthly reports and have them uploaded into the national portal. This is an extremely time-consuming and error-prone process, which could be made automated if the national portal had provided public access to their APIs. However, we have now seen interoperability being implemented in the recent CoWIN rollout; for example, personal details registered in the Aarogya Setu can be used to log-in to CoWIN (see Fig 2). The CoWIN website (see cowin.mohw.in) has also published its various APIs and data standards, enabling potentially increased interoperability with other systems. This development also indicates the learning which has taken place across the deployment of the two systems in the course of the pandemic.

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The pandemic has particularly highlighted the need for sharing data across systems, enabling policymakers, care providers and the public to access data relevant for them and to make best use of data which has already been collected and to access required services, such as the vaccinations. Having worked with supporting some states on the COVID-19 HIS response, we have seen that at the state level, multiple systems are in use for different purposes and often there are limited mechanisms to share data between them. However, technically it is possible to build interoperability if enabled by an informed leadership, as our experience in some states (e.g. Punjab) has been. In most states, the multiple systems include i) a central COVID-19 reporting system introduced by the Ministry of Health (MoH) and Indian Council of Medical Research (ICMR); ii) the Aarogya Setu app, and web portal for management of data for user self-assessments, positive cases, and contact tracing activities; iii) a surveillance App collecting household-level data of individual screened, and the management of positive cases through hospitalisation, home quarantine and isolation; and, iv) the current CoWIN App for enabling vaccination rollout. Additionally, there are also the other routinely running systems such as

the HMIS, Integrated Disease Surveillance Programme and various others, which would be collecting some facets of required data. Ideally, these systems should be able to exchange relevant data and get it into a shared repository to generate required indicators, reports and trends for different stakeholders. It required quite an intensive effort and time to build these mechanisms of integration, something which is technically relatively easy to be automated if interoperability mechanisms were in place. The Aarogya Setu – CoWIN interoperability potentially holds the promise of more such data sharing mechanisms being put in place in the future.

As the Sri Lanka case described above has vividly illustrated that the need for interoperability is far more critical and complex in situations of pandemic management, as there are multiple institutions and systems involved. For example, airport entry information management is the responsibility of the home department, which needs to share data with the health department who are responsible for follow-up and treat suspect cases. Similarly, information on infection hot spots, available with the health department needs to be shared with the police responsible for enforcing lockdown measures. Each department has its respective systems, built on different platforms and collecting varying types of data. It is infeasible for the government to use one monolithic system for all, instead strong governance mechanisms are needed to establish data sharing protocols and ensuring this takes place while protecting data security and privacy. This is as much a technical challenge as it is an institutional one (<u>Amarakoon et al.</u> 2020).

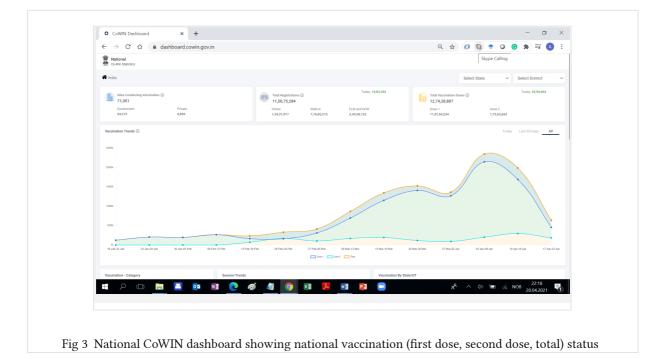
So, what lessons can be drawn from this discussion for strengthening Indian public HIS, with a particular focus on outbreak management? We draw four key lessons: i) the need to develop hybrid centralized-decentralized models, where the central structure enables rapid decisions and enables the implementation frameworks including establishing data standards; ii) the centre should enable a long-term and broad-based capacity building programme anchored in the national university or medical research structure, to develop hybrid health informatics capacity dedicated to support public systems strengthening; iii) the use of free and opensource digital platforms which can be adapted to different use cases rapidly and at minimum costs and which enable interoperability; and, iv) ensuring robust governance mechanisms to ensure data interoperability mechanisms enable rapid sharing and use of data.

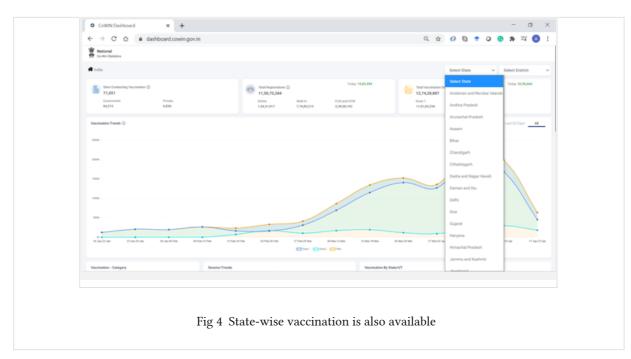
'Doing more with less' data

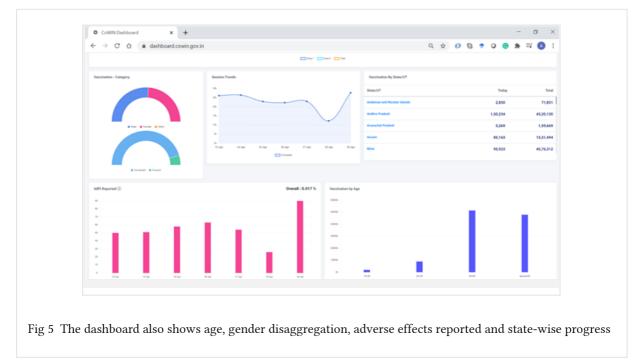
While the time spent by the health workers/providers on data recording/reporting *vis-à-vis* care providing services, has long been debated (<u>Mukherjee 2015</u>), with data reporting load on health workers adding excessive pressure on care provision. However, the COVID vaccination reporting system seems to be ushering in a change. The data required to register for vaccination in the CoWIN platform include – name, date of birth, phone number (this, too, is added by the citizen in case of self-registration), and at the time of vaccination, the health worker adds a batch number of the vial and name of the vaccine administered. In total, only five data elements are used for completing vaccination for each citizen, which stands in stark

contrast to the 112 data elements collected for each pregnancy, 89 data elements for each malaria patient, 94 data elements for each leprosy patient, Though it can be argued that other health programs involve following a patient for longer periods, while COVID vaccination is a shorter follow-up duration, still this has definitely shown empirical evidence 'to do more with less' concerning data.

Even though the data collected for COVID vaccination is minimal, the data is shared in the public domain on a real-time basis on the CoWIN dashboard with public access (see figures below) This is a very welcome change in Indian health systems, which are famous for keeping the data in the black-box of the bureaucracy and not making it available to the public. Though the data black-boxing might still be true for COVID-19 case and death reporting, the vaccination reporting is ushering in a welcome change, which is a welcome learning experience to take into other health programs, where for the citizens to get any data would typically involve filing an appeal through the Right to Information (RTI) process.







LESSON 2: BUILDING RELEVANCE and TRUST

Relevance concerns the ability of the HIS to collect data that is required to support decisions to address the health problems at hand. Relevance is shaped by three key conditions. The first concerns *what* data is collected and its relevance for supporting action to address local challenges. The second concerns *how* the data is used for action. Information is only a

necessary but not sufficient condition for supporting action, which also requires other enabling conditions such as political will, governance, and resources. Also, crucial here is *what incentives* exist for the citizens in sharing their data. The third concerns *who* is the data made available to, particularly important is the need to make data available to the public whose lives are fundamentally at stake.

Collecting relevant data to support action

Public HIS in India, and most Low and Lower Middle-Income Countries (LLMICs), are notorious for collecting data, which is largely not relevant for supporting action to improve health services delivery. Or rather, they collect huge amounts of data, which by and large are used primarily to fulfil bureaucratic purposes of upward reporting for control purposes and only marginally for strengthening local-level health services delivery (<u>Sahay et al. 2017</u>).

We illustrate the above challenge by some historical examples from India before discussing the issue in the specific case of the COVID-19 response. In 2008, under the National Rural Health Mission (NRHM) initiative, there was a focussed effort to reform the national HIS, including making it more decentralized, integrated and enabling better support for evidence-based decision making. The reform process, in which two of the authors were involved, analysed what data was being collected and how it is being used. It was found that an ANM was typically collecting about 3000 data elements per month, and only less than 5% of this data was actually used for generating indicators, a proxy of its relevance for decision making. This raised the important question of why the remaining 95% of data was being collected? To illustrate, every data element collected (e.g. Antenatal Care (ANC) first visits) was broken up into three elements (ANC first visits Schedule Caste, ANC first visits Schedule Tribes, ANC first visits Others). During the brainstorming discussions, the Mission Director, NRHM, asked the health programme people if such disaggregated data was needed for programme management and whether any indicators were generated from it? The response was, no, and that it was only being collected in case a Parliament question is raised. The Mission Director went on to scrap this disaggregation and also bought in a number of other innovative changes, leading to a reduction of more than 90% of the data to be collected. This helped to enhance the relevance of the HMIS and dramatically reduce the data collection burden of the ANMs.

To implement the reforms carried out in terms of the redesign of the datasets, the Mission Director wrote a visionary letter to all states that they should only report district level aggregated data to the national level, and if they needed sub-district level data, that should be managed and retained at the state level. However, more than 10 years on, that directive has been buried under the weight of bureaucracy and technology. In the MCTS case cited earlier, all individual-level data (nearly 200 parameters per person record) gets transmitted to national servers! Sahay and Mukherjee (<u>Sahay et al. 2020</u>) have described that in a state-level HMIS, typically 70% of data is being systematically reported as a 'zero' or 'null' value, clearly implying that data is typically not being used for decision making. Then the question can be

rightly asked, as to why this data continues to be collected? In response, the proponents will argue that given the advances in computing power and server capacity, it is not a problem to collect such high volumes of data in national servers. Further, another argument typically given is that "we may need all this data at a future point of time." Such data can be categorized as being not essential and 'must know' but as desirable and 'nice to know.' However, such data has questionable relevance and at the same time adds a huge data load on the data providers – the hapless ANMs.

The CoWIN App contains relatively limited data and is easy to fill. On one log-in, the citizen can book an appointment for the first dose or second dose for himself/herself and four others, by entering the PIN code of the preferred place for vaccination (see Fig.6) and only the year of birth (no date of birth is required). There is a purpose for each data field-collected, for example, the PIN code allows you to see the different vaccination centers (public and private) in your area, and the year field helps check your eligibility for your vaccination (for example, over 18-years). The system gives the option of multiple identification means to be used, such as passports, Aadhar cards, birth certificates, election cards, and also Aarogya Setu logins. In this way, CoWIN represents a more simplified and non-threatening form of data collection, with concrete associated purposes. The website also provides various interesting aggregated statistics (numbers vaccinated, registered, etc.) by states and districts. Vaccine certificates (see Fig 7) can also be easily downloaded from the same website, which also provides useful information on the batch number of the vaccination administered and the name of the health worker. Citizens who are unable to register their details into the App can have them filled through the support staff at the vaccination centers, and there is only a 10-15 minutes waiting time to receive the vaccination. Further, house to house outreach is also being done to promote citizens' uptake of the vaccination. The overall health system including the HIS is thus in a holistic and integrated manner aimed at promoting demand, along with providing tangible incentives for the citizen, in addition of course to actually getting the vaccination.

Ministry of Health and Family Welfare	Co-WIN Waving Over COVID-	19							Logout
		Apr 05 2021	Apr 06 2021	Apr 07 2021	Apr 08 2021	Apr 09 2021	Apr 10 2021	Apr 11 2021	,
CLOUDNINE BELLAR BBMP, Kamataka, Sr	_		100	100	100	м			
Columbia Asla Sarja BBMP, Kamataka, S									
Dr Sunny Medical Co BBMP, Kamataka, Sr		*	100	97					
MAYA HOSPITAL P3 BBMP, Kamataka, Sr		92	100		100	100	9		
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Both the apps are oriented in different degrees to supporting action, which represents a welcome departure from earlier systems such as the MCTS, which has been criticized for not primarily focused on supporting care (<u>Mukherjee 2017</u>). Overall, it does seem the CoWIN App had improved in terms of the amount and type of data collected, identifying that with a clear purpose, and providing specific incentives to citizens to share personal data. CoWIN provides more specific resources for enabling data sharing and represents a 'one-shop stop' for citizens concerning vaccination (registration, appointment scheduling, certification, viewing statistics, etc.). Concerns of privacy remain in both the apps, reflecting a broader lack in government systems, and (re)emphasizes an immediate need for strengthening. This of course is a larger challenge in such systems the world over where concerns of privacy and provision of individual care needs to be balanced.

This issue of purposeful collection of data for the citizen's benefit, in this case, protection via contact alerts, vaccination facilitation, information sharing, etc., bring forth the issue of proportionality and minimization in public health. While the World Medical Association's (WMA) focus is on individual rights and protecting individuals from potential harm, in public health, "the coercion of individuals can be justified on the grounds of public interest, but the incursion on individual liberty must be proportional to the anticipated public benefit" (<u>Ballantyne 2019</u>). While some researchers identify in public health ethics a rich framework for researchers, data communities and stakeholders to help make this balance (<u>Ballantyne 2019</u>), others say the argument that protection of public health should take precedence over data

protection is neither ethically nor legally correct. They claim it cannot only affect the person from whom the data originates but also third parties who need to act because of this data processing (e.g. obligation to self-isolate in contrast to citizen responsibility). Also, more importantly, perhaps the understanding that as soon as such a pandemic is over, data collected for reasons such as tracing and vaccination certificates are no longer used (<u>Schmidhuber & Stöger 2021</u>).

Trusting the openness

Population participation is essential in the gathering of relevant data, which is built on trust over time involving institutional structures that provide for robust governance and transparency in data sharing and use. This is particularly pertinent in the COVID-19 case which primarily deals with personal data. Clarity needs to exist on the ownership of the data once this has been anonymised and possibly merged with a larger national database (<u>Agrawal</u> 2020; <u>Chakravarty 2020</u>). Where the data goes and to whom, are issues of utmost importance and should not remain unknown to the citizens (<u>Kodali 2020</u>). There are also questions around data sharing. While we have emphasized it is important, legal scholars point out that 'sharing of such data between ministries, not all of which directly deal with health and hygiene, and the subsequent use by them of this enormous database, is another key worry for the privacy advocates' (<u>Sen and Tarafdar 2020</u>). In India, there are limited legal mechanisms for data protection to citizens against encroachments by public and private data aggregators.

These issues have been emphasized in the current crisis as telehealth, telemedicine and video consultations have become a necessity given the need for remote consultations and for the rich who want care in their homes (<u>Ateriya et al. 2018</u>). These concerns are also ongoing with the <u>E-Sanjeevani platform</u> launched across India offering online consultations with doctors and specialists registered on the platform. Concerns around the quality of clinical management, privacy and safety of the online consultation are fundamentally dependent on meeting basic governance policies (<u>Greenhalgh et al. 2020</u>; <u>Singh 2020</u>). Under the NDHM, a draft <u>National Health</u> <u>Data Management Policy</u> (<u>MoH</u>FW, 2020) is under development and has recently been put out for public consultation. However, to make it effective, strong legal mechanisms need to be in place (<u>Deccan Herald 2020</u>).

In terms of citizens trust in ICT initiatives for the pandemic response, the case of South Korea is exemplary (<u>GoROK 2020</u>). Some key points of learning include:

 To help social distancing. Korean government used the Cellular Broadcasting Service (CBS) to transmit emergency alert text messages. They opened a website to provide information about companies providing solutions for remote working, education, and doctors providing telemedicine services. These measures helped the use of effective social distancing measures in society.
To locate COVID-19 cases with speedy testing. Five diagnostic reagent companies obtained emergency use approval to produce RT-PCR reagents. Artificial Intelligence (AI) played a significant role in supporting researchers and healthcare professionals in the diagnosis and screening of patients with severe symptoms, as well as developing appropriate responses. In addition, the famous "Walk-Thru" testing stations allowed quick collection of samples with minimal contact.

3. To quickly trace COVID-19 cases. A diagnostic kit was developed by a Korean biotech company using AI techniques and high-performance computing. The governments had historically been encouraging investments in modern ICT techniques, such as AI, which were applied rapidly to speed up the scale and coverage of testing.

4. To facilitate COVID-19 treatment. AI was used to reduce the time required to develop medicine, by learning and making deductions based on the virus and other medical data. This modern knowledge was used by companies to develop new medicines, to analyze the interaction of drug and protein, and propose candidate medicines.

5. To flatten the curve on COVID-19. Key information such as the accumulated count by region and number of tests performed was summarized and provided as visualization data through the website. Information on providing overseas travel history, finding COVID-19 screening centers, early-detecting of patients, using epidemiologic surveys and isolating the close contacts of a patient was provided. Real-time data of publicly distributed face masks were provided to people through mobile applications and web services, reducing confusion and inconvenience while raising distribution efficiency.

In summary, the Korean experience provides three key learnings on how ICTs can be used to generate relevant data, which goes a long way in strengthening already existing trust between citizens and the state: i) ICTs should be used to help generate opportunities through the crisis building upon the state-of-the-art knowledge; ii) all kinds of relevant information should be made readily available to all, treated as a public good; iii) the expertise of companies should be leveraged upon to create public-private partnerships leveraging further on historical investments made by the government on R&D. All these could be leveraged to good effect, which helped Korea successfully flatten the curve. Most of all, the trust of citizens in the government and broad compliance to the measures taken, helped make Korea a best-case global example on how to engage with the pandemic. There have been questions raised on methods used to track criminals being repurposed for public health use (<u>BBC News 2020</u>), but not overtly rejected by citizens.

LESSON 3: BUILDING PUBLIC HEALTH FRIENDLINESS

Public health friendliness for the HIS, similarly, could be expressed as the ability to support the population at large in an equitable manner. Two ways of ensuring HISs are public health-friendly, then, are: (i) by strengthening public-facing information systems and, (ii) designing systems based on public health expertise.

Strengthening public health content in information for the public:

Information sharing has been at the crux of the COVID-19 pandemic, across governments, scientists, health professionals and the common public. Although formal channels of communication were activated in most cases, the need for a more expanded chain of digital

information sources is crucial. Drawing from the South Korea example again, their model of reaching out to the public for the early management of the pandemic proved to be great learning from their experience of the 2003 SARS outbreak. They had legislations in place defining the role of government and private actors alike to engage with the public in transparent and regular communication. Key emergency information on the novel virus and ways to maintain distancing were spread through targeted SMS messages through the already established system via the National Disaster and Safety Status Control Center, accompanied by updated online information and press briefings twice a day. Free smartphone apps, also provided by the government, flagged infection hotspots with text alerts on testing and local cases (GoROK 2020). Other countries soon adopted this model with health departments and scientists, in some cases, providing data on the COVID-19 situation. Initiatives in India, too, took the opportunities in ICTs to engage with the pandemic: MyGov App, GoK Direct, Delhi Corona App, Sandhane, Aarogya Setu, and MahaKavach App, to name a few, were some apps released by the government to catalyse and facilitate processes involved in the spread of information and disease control. However, there was not the same degree of public-facing information, as compared to the South Korean case. For example, the first national lockdown was announced a few hours before it came into effect, provided citizens with little time and space to get prepared for a 6-weeks shut down of all forms of social and economic life. This, as already pointed out, led to immense hardships for citizens, particularly migrant workers living many thousand miles away from their homes.

In addition to digital solutions, local news channels and social media have acted as large sources of health information capable of influencing populations. Poor health media literacy, though, has fuelled feelings of uncertainties, fear and a loss of trust, while poorly sourced health information on the internet and otherwise have proven detrimental to the collaborative responses required to reduce transmission (<u>Hernández-García et al. 2020</u>; <u>Wang et al. 2020</u>). Fake or unverified information on social media such as false cures, rumours of lockdowns and community-based conspiracies have been rife also in India (<u>Bajpai et al. 2020</u>). While 'false news' now represents a global challenge, debunking the flow of such false information is crucial to avoid panic in citizens, reducing uncertainty and enhance trust (<u>Chatterjee 2020</u>; <u>Wang et al. 2020</u>). In the current context of digital inter-connectedness and weak regulatory systems, it becomes nearly impossible to block out social media messaging. What is important, as the Korea case has illustrated, the government needs to build their own credible sources of information, which is fundamentally informed by respected scientists and institutions and disseminated widely through appropriate media to citizens on a regular basis (<u>Gorok 2020</u>).

Designing systems based on public health expertise

A key critique in information systems research has been overriding of system design by the technologists while ignoring domain experts. We have seen this too often within the Indian health system, for example, the Electronic Medical Records (EMR) system developed by the Centre for Development of Advanced Computing (C-DAC) with limited involvement of

hospital staff (nurses, doctors, etc.), or the MCTS system developed in a top-down manner by National Informatics Centre (NIC) with limited engagement with public health experts and understanding of the work practices of the end-users – the ANMs. And with the COVID-19 surveillance system, the cycle repeats. As <u>Priya et al. 2020</u> note, the national response to the COVID-19 pandemic has been shaped by a narrative generated by the mathematical models of the anticipated spread of the novel coronavirus. And the graphs generated by these models pictorially represented steep and tall peaks of cases and deaths, which were then superimposed by a flattened graph that projected the impact of strong 'social distancing' measures. All while ignoring the inputs or advice from public health experts, which is of abundance in the country.

Priya notes that the ministry largely ignored its own epidemiologists and health systems teams, and also the National Centre for Disease Control (NCDC) and the National Disaster Management Authority (NDMA), institutions created to respond to health emergencies such as the COVID-19 pandemic. Instead, their reliance was primarily on mathematical and statistical models advised by US-based consultancy (NDTV 2020). Though we still are amid the pandemic with none knowing the end, we still have time to change the course from 'COVID action' to 'public health response' based on learning from what worked, and what needs to change. As part of the 'public health response,' design surveillance systems with public health experts that should be able to control the present situation need to take a long-term view even while we engage in shorter-term firefighting during the pandemic. Another important learning emerging has been the importance of 'inclusion of local institutions' in planning action which affects the citizens at large. As India announced national lockdown centrally, this incapacitated the local health system to respond to the local needs, while the local community looked at 'nearest' health personnel for the 'response,' for example the field level care providers, responsible to respond to local communities, were themselves as unaware of the actions/plans as the community itself. As discussed earlier, Aarogya Setu primarily catered to the central COVID action centre, putting to the background, the need for local action. CoWIN comes across as a more decentralized and citizen-friendly system.

India did not have a Fauci face of their own for the COVID-19 pandemic. More involvement is known of the US-based consulting firm than of national institutions like the National Centre for Disease Control (NCDC) in the planning and decision making during this pandemic. Two statements made by the joint task force of the Indian Public Health Association and Indian Association of Preventive and Social Medicine, joined later by the Indian Association of Epidemiologists, highlighted the need for a review of the lockdown, cluster restrictions, physical distancing rather than social distancing, extensive active surveillance, along with long-term measures such as sensitization of community leaders, service and research upscale of public health, clinical and social care. The need for a panel of interdisciplinary public health and preventive health experts and social scientists to address the public health crises at all administrative levels was called, along with the need for open and transparent data sharing with scientists, public health professionals and the public. While ICT expertise is required for the know-how of the technology, input from public health experts with epidemiology, health systems strengthening and community perspectives is vital (<u>Priva et al. 2020</u>). <u>Gilson et al. 2017</u> also

reinstate the need to nurture the everyday resilience in health systems, not by only providing technology, but developing people's agency through the development of organizational capacities via the building and sharing of good relationships, routines and resources.

What lessons can we draw from this discussion for the Indian public health context? We draw the following key lessons: (i) the need for information systems response to be driven by public health expertise and not computer technologists. This is fundamental if we want systems to be public health-friendly and relevant for strengthening local action. (ii) the need for strong public health face to be interfacing with the public, and not bureaucrats and politicians. It is in science people tend to trust, and who would be better believed? This would help to make effective interventions such as social distancing and wearing masks more acceptable.

Some key HIS learnings identified are summarized in Table 2.

Building agility	Building relevance and trust	Building public health friendliness		
Decentralised information for enabling local action	Collecting relevant data to support action	Strengthening public health content in		
		information for the public		
Participatory governance – informed	Relevance of who the data is	Need for public facing		
public discussion	shared with	scientifically informed		
		messages		
Local governance and space for innovation	Strengthening of data	Timely provision of official		
	sharing governance	information platforms to		
		reduce mis-/dis-information		
Use of existing systems and capacities	Synchronization of state and			
	central policies			
	Integration with overall			
	health systems			
Enabling integration and data sharing	Trusting the openness	Designing systems based		
across systems		on public health expertise		
Use of free and open source digital	Transparency in use of data	Collaboration of		
platforms		technologists with health		
-		experts in the fields		
Increased interoperability across digital	Clarity on ownership of	Inclusion of local		
systems	data	institutions to plan local		
-		action		

Table 2 Summary of identified key HIS learnings

Less data collection - doing more with less	Participatory development	Nurture and develop local
	of systems	people's agency
Collection of purposeful information –	Sharing data in public	Bringing public health into
maintain the proportionality	domain	public discourse
		Demand-driven vs. supply-
		driven

CONCLUSION

Even within the relatively short span of a year, moving from Aarogya Setu to CoWIN, the government has demonstrated how the digital can be more effectively managed and made more relevant and trustworthy for the citizens. Surely, these changes are also relevant for our routine HIS dealing with diseases like malaria, TB, leprosy, where the morbidity and mortality toll may be even higher than in the case of the current pandemic. There are clear learnings from this COVID case that can be sensitively considered and adapted to these other disease contexts. Further, experiences from other countries such as Sri Lanka and South Korea (<u>Amarakoon et al. 2020; GoROK 2020</u>), also provide new avenues for learning. We have focused on describing three key areas of learning - agility, relevance and public health friendliness. Underlying these learnings is the need for adopting health systems strengthening perspective, building citizen trust in the state, and the use of free and open-source digital platforms which come without licensing encumbrances and provide the material features to build solutions with agility while ensuring data sharing, in light of unknown futures.

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